VISION IMPAIRMENT IN THE COMMUNITY

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Vision Impairment in the Community

1. Research Plan

A. Introduction and Specific Aims

Employing procedures which have been tested and developed in a one-year pilot study*, our study will (a) establish the magnitude of vision impairment in a large metropolitan area -- Cleveland, Ohio; (b) describe the physical and social characteristics of the visually impaired population -- including those unknown to agencies concerned with this group and those not traditionally regarded as blind; (c) lay groundwork for follow-up studies of the visually impaired -- especially their needs for medical and social services, adjustment to eye disorders, and the roles of family and community in determining patterns of adjustment; and (d) establish a model for studying other chronic conditions and impairments and use that model for a pilot survey of heart conditions

(1) Current Status of Work in the Area.

a. Estimates of the prevalence of legal blindness. Legal blindness** has not been recorded in the decennial census since 1930. Thirty-eight states maintain registers of blind residents, but only eight states have mandatory reporting of new cases of blindness. According to best estimates, the prevalence of blindness in the U.S. is slightly more than two per thousand population -- yielding a total of approximately 385,000; there is reason to believe that prevalence rates vary among the regions. The Model Reporting Area for Blindness Statistics, now being administered by the

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* National Institutes of Health grant NB 04282-01, "An Epidemiological Survey of Visual Impairment." See Section 2.A. and the Appendix for details.

** Defined as central visual acuity of 20/200 or less in the better eye, with correcting glasses; or central visual acuity of more than 20/200 if there is a field defect in which the peripheral field has contracted to such an extent that the widest diameter of visual field subtends an angular distance no greater than 20 degrees.

National Institute of Neurological Diseases and Blindness in cooperation with nine states, will eventually have a salutary effect on this neglected area of health bookkeeping. Meanwhile, however, there is a serious lack of reliable information about the number and characteristics of the blind -- particularly at community levels.

b. The National Health Survey and "severe visual impairment." Recently, further doubt about the reliability of accepted blindness statistics has been raised by the U.S. National Health Survey in its studies of impairments. Using a broader concept of severe visual impairment (defined as inability to read newspaper print even with glasses) and basing its findings on a nationwide sample survey of households, the Health Survey has reported nearly three times as many severely impaired persons in the U.S. as had been indicated by previous estimates of the blind population. Not only has the Health Survey made estimates of the prevalence of vision impairment, it has also published estimates for major geographical regions, urban-rural residence, and a small number of metropolitan areas (not including Cleveland). The criteria used by the Health Survey for measuring vision impairment have yet to be clinically validated,* and in any case crude prevalence rates alone, although useful as guidelines, do not necessarily shed light on important sub-groups within the local population (e.g. Negroes, low-income groups, etc.).

c. Other surveys of vision impairment. A number of major community health surveys have produced prevalence data on vision impairment -- for example, the Washington Heights Survey in New York City, and the Baltimore Study of Chronic Illness -- but none of these has focused specifically on vision impairment. Like these surveys and the National Health Survey itself, our proposed study

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* The American Foundation for the Blind is currently planning with the U.S. National Health Survey a clinical follow-up validation of its visual impairment data. However, results from this study will not be available before the survey proposed here is undertaken.

will be based on a household probability sample. Unlike the National Health Survey, our study will take place in a limited geographical area. So far as we know, it will be the first to focus on vision impairment -- producing not only prevalence rates, but also intensive follow-up interviews with and examinations of the visually impaired.

(2) Rationale

a. Criteria for defining vision impairment. Blindness as defined by law is arbitrary in the sense that it includes some persons who function nearly as well as "normally" sighted persons and excludes others such as the "functionally blind." Therefore, in our pilot study and in the survey proposed here, we have adopted National Health Survey criteria for defining vision impairment. As noted before, the Health Survey defines "severe visual impairment" as inability to read newspaper print even with glasses. Our justification for including such cases in our study is that an appreciable number of them are limited in daily activities and mobility precisely because of their impairment. In addition there are many more persons described by the National Health Survey as suffering from "other visual impairments" -- which includes those who are blind in one eye, or persons who have poor vision or trouble with seeing in one or both eyes but who can read ordinary newspaper print. While we are primarily concerned with the severely impaired, we cannot ignore those with moderate or slight impairments because not all persons defined by law as blind fall into the Health Survey definition of severe impairment -- for example, blind persons who can read ordinary newspaper print with optical aids. Some people with moderate visual impairments are so seriously handicapped as to limit physical and social activities, and hence our wish to include these persons in our study. Although not yet clinically validated, the National Health Survey criteria clearly suggest the presence of a much larger visually impaired population than

is indicated by estimates of the legally blind.

b. Strategy for locating cases of vision impairment. One of our basic assumptions is that a large probability sample of households will be essential to determine the magnitude of visual impairment and to provide a representative number of cases for detailed analysis. Without such a wide sample, we would miss both the hidden or unknown blind and the far larger number of persons who are severely impaired but not blind under the law. In most states and large cities it is chiefly legally blind persons receiving public assistance or those getting special services (educational, vocational, recreational, etc.) who become known to and registered by public and private agencies. As a result, a serious bias exists in such lists of blind persons, and we may assume that an important minority of the legally blind population is unaccounted for. In Cleveland for example, more than 2,000 blind residents are known to the local Society for the Blind, but our pilot study suggests there may be at least half as many blind persons who are unknown to local health and welfare agencies either because the agencies have been unable to reach them or because they do not want to be reached. One of our primary aims is to get information about this hidden element. As for the visually impaired who are not blind according to law, since there is no list or registration of such cases, there is of course no way to reach them other than with a household sample.

c. Why Cleveland? Cleveland has been selected as the site of our proposed survey for a number of reasons. First, the pilot study which Western Reserve University and American Foundation for the Blind conducted early in 1963 was done in Cleveland. This means that the nucleus of a field staff has already been recruited and trained. Second, while the pilot study was restricted to the city of Cleveland, our plan now is to draw our sample from all of Cuyahoga County, which includes Cleveland and most of its suburbs. An extremely

diversified area in terms of industry, occupation, socio-economic characteristics age and ethnic groups, metropolitan Cleveland offers a satisfactory cross-section of the population from which to select a sample. Third, Western Reserve University (through its Department of Preventive Medicine and its Department of Sociology) has sponsored or conducted numerous studies of chronic disease in the Cleveland area and will assume responsibility for the present study. Fourth, the Cleveland Society for the Blind has offered its cooperation, as have the Health Council of the Cleveland Welfare Federation and the Cleveland Health Department.

(3) Aims.

a. Prevalence. Our immediate aim is to determine the extent of vision impairment in metropolitan Cleveland by conducting a screening of approximately four percent (20,000) of the households in the area. This large-scale screening will also provide data on other impairments and chronic conditions.

b. Characteristics. Another primary aim is to describe the physical and social characteristics of the visually impaired population identified in our screening operation. Here we are interested not only in identifying and comparing sub-groups within the visually impaired population (legally blind, other severe impairments, etc.) but also in comparing the visually impaired with "normals" in the population.

c. Validating NHS Data. A third aim is to validate the criteria which the National Health Survey has used in its studies of visual impairment. This will provide an independent check from at least one metropolitan area on the Health Survey's own clinical follow-up study.

d. Follow-up Studies. Our study is intended to lay the groundwork for further research on eye disorders in the same geographical area. Vision impairment is not just a health problem; it is also a social problem resulting

from pitying attitudes toward blindness and the tradition of isolating many blind persons from community life by institutionalizing their education, work, and recreation. Precisely because this double aspect to the problem exists, we plan a major follow-up study in later phases of our research program on community aspects of adjustment to vision impairment. By recontacting sub-samples of the visually impaired population identified in our screening survey along with sample surveys of the known legally blind and selected groups in the sighted population, we will seek information about such problems as the need of visually impaired persons for social services, the role of the family and other intermediaries (chiefly social workers and their agencies) in determining successful or unsuccessful patterns of social adjustment; and public attitudes regarding blindness and the extent to which such attitudes are expressed or reflected in the relations between visually impaired persons and their sighted neighbors.

e. A Research Model. Finally, and by no means least important, we aim to establish a model for the study of other chronic conditions and impairments and to apply that model in a survey of heart conditions reported in our screening of households.

B. Methods of Procedure. (see time schedule on page 7.)

(1) Sampling and Interviewing Procedures.

While a large proportion of the legally blind population can be approached directly with the aid of local agencies and their client lists, there is, of course, no direct access to the unknown blind or to most persons with severe or moderate vision impairments. To get reliable data on their number and characteristics, we plan to conduct a screening of households in Cuyahoga County.

a. Sample size. As in almost any study of a relatively rare attribute or condition, our aim is to obtain a statistically significant number of cases while also holding field costs to a minimum. We estimate that the prevalence of legal blindness in metropolitan Cleveland is approximately two per

B. Methods of Procedure

Summary of Scheduled Procedures 7/1/64 -- 6/31/65*

Time B

Time Budget	Procedure	Number of Cases
7/1/64 - 7/30/64	Pretest	100
8/1/64 - 10/31/64	Screenings	
	a. Telephone	15,000
	b. Non-Telephone	1,250
11/1/64 - 2/29/65	Follow-Up Interviews and Clinical Examinations	
	a. Interviews and home eye tests of moderately impaired	260
	b. Interviews and home eye tests of severely impaired	330
	c. Interviews and home eye tests of legally blind	200
	d. Clinical examinations of 33% subsample of groups b,c, and d	265
	e. Clinical examinations for heart disease	100
3/1/65 - 6/30/65	Data Processing, Analysis, Preliminary Report, Beginning of Intensive Studies	

* This is an estimated time and procedure schedule. The pretest period is short since techniques and instruments were developed in the pilot study. An initial sampling of 20,000 households (four percent) of the metropolitan area will be made. It is expected that 15,000 will have listed phones. A 25% sample (1,250) of non-telephone households will be drawn. An estimated 1,100 cases of visual impairment will be screened by both methods.

Seven hundred and seventy are expected to be moderately impaired, of which 33 percent or 260 are to be interviewed and vision tested in the home. The 330 severely impaired will be interviewed and tested as well as the 200 legally blind sample obtained from the roster of the Cleveland Society for the Blind. Approximately one-third, or 265, of the 790 will be given the opportunity to take a clinical examination. An estimated 100 persons will be examined for evidence of heart disease.

thousand population,* with the rate for hidden or unknown blind probably half as great. The question is what sample size will give us an adequate number of cases to provide us not only with gross figures for vision impairment, but also with data for sub-groups within the population (e.g. age, race, sex, etc.). In developing our plans, we have considered a number of alternative sampling operations. For example, a six percent sample of households in Cuyahoga County would yield approximately 200 cases of blindness and a total of approximately 2,000 cases of all vision impairments. On the other hand, a two percent sample would yield only 65 cases of blindness; for sub-groups within the population, the number of cases would be insignificantly small (for example, there would be only eight blind persons under 25 years of age in such a sample). Therefore, we have concluded that a four percent sample of households would be the smallest one which would give us an adequate number of cases of blindness.

In approaching the problem of sample size, we have made a number of assumptions about the prevalence of visual impairment in the general population and in specific age groups. These assumptions are based on the nationwide sample surveys conducted by the National Health Survey, our own pilot study in Cleveland, and the blindness registers of two states in the northeast (New York and Massachusetts).** Assuming approximately 20 visually impaired persons per thousand population in Cuyahoga County and an average of 3.3 persons in each household in the area (according to the 1960 U.S. Census), we have calculated that some 20,000 households (66,000 individuals) would have to be screened in

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* This estimate is derived from that of Dr. Ralph Hurlin for the state of Ohio, "Estimated Prevalence of Blindness in the United States and in Individual States, 1960," The Sight-Saving Review, Vol. XXXII, No. 1, Spring, 1962.

** These two states were selected because they are similar in many demographic characteristics to Ohio and are among the few to have issued fairly comprehensive statistics on blindness.

order to produce the four percent sample which we propose. We have calculated that in a probability sample of this size at the 95 percent confidence level, one could expect to find a fluctuation of approximately 1 for all cases of vision impairment -- that is, a range from 19 to 21 per thousand. For "severe" impairment (as defined by the National Health Survey), we estimate that in 95 out of 100 samplings one could expect to find a fluctuation of .6 -- i.e. a range from 5.4 to 6.6 per thousand. And as for the rate of blindness, we estimate a fluctuation of .4, or a range from 1.6 to 2.4 per thousand population.*

B. Sampling procedure. In view of the relatively low prevalence of vision impairments and the large number of persons to be reached, a household screening based entirely on personal visits would be prohibitively expensive. An alternative approach and the one we plan to follow is to rely chiefly but not entirely on a telephone screening of households. Will this approach introduce bias into the sample? A recent survey conducted by the California Department of Public Health shows that a considerable amount of health data can be obtained by means of telephone interviews and that with respect to validity, rate of return, and rate of completeness, the telephone method is as reliable as mail questionnaires or personal visits.**

Our own pilot study, which was designed primarily to test the telephone strategy for getting visual impairment prevalence data, is also encouraging on this score. Thus, in our telephone sample, we obtained a prevalence rate for all visual impairments of 19.3 per thousand population, with a sampling

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* We have made similar calculations for expected prevalence rates in specific age groups. To illustrate, we estimate that the prevalence rate of all vision impairments will be 5.5 per thousand for persons under 25 years of age, and that in 95 out of 100 samplings one could expect a fluctuation of .9, or a range from 4.6 to 6.4 per thousand. To take another example, we estimate that the prevalence of blindness in the 45-64 age group will be two per thousand, and that in 95 out of 100 samplings one could anticipate a fluctuation of .7, or a range from 1.3 to 2.7 per thousand. These calculations are based on the assumption that we will draw a simple random sample.

** For discussion of this study, see Section 2.C.

error of plus or minus three at the 95 percent confidence level. This may be compared with the National Health Survey's prevalence rate of 19.8 per thousand, with a sampling error of 1.4. In short, the difference was relatively small. Furthermore, a special study which we made of a sample of some 180 legally blind persons drawn at random from the client list at the Cleveland Society for the Blind showed that the proportion of blind persons with telephones was approximately the same as in the general population. In other words, our experience in the pilot study suggests that the telephone strategy is unlikely to produce bias in prevalence data* or to discriminate against the most severely impaired (the legally blind).

Nevertheless, our pilot study also revealed that households without telephones (which includes families with unlisted phones) may have a higher prevalence rate of vision impairment than homes with telephones. As may be expected, there were significant differences between the two populations (telephone and non-telephone) with respect to certain demographic characteristics.

Therefore, our plan is to draw a random sample of households in Cuyahoga Country from up-to-date city directories. The households selected will then be checked against the most recent Street Address Telephone Directory to identify the telephone numbers of those with listed phones. The total sample will then divide into a telephone sample and a non-phone sample (including unlisted phones).

All telephone households will be contacted. However, to reduce costs, we propose to sub-sample the non-telephone households (which will require personal visits for screening). In our pilot study, since we found that approximately one out of four of the households in our basic sample was without a listed telephone, for budgetary reasons we were forced to sub-sample approximately one-third

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* The problem of under-reporting is discussed below.

of this non-telephone group. We intend to follow this procedure in the larger survey proposed here. Thus, out of some 20,000 households in our four percent sample, we estimate that approximately 15,000 will have listed telephones -- leaving some 5,000 to be screened in person. Our plan is to sub-sample 25 percent (or 1,250) of the non-telephone households. But since (as our pilot study showed) the prevalence of vision impairment is likely to be higher in non-telephone than in telephone households, we estimate that the total sample will yield approximately 1,100 cases of vision impairment. Of the 1,100 we estimate (again drawing on National Health Survey reports and our own pilot study) that approximately 770 or 14 per thousand will be only moderately or slightly impaired and that the remaining 330 or six per thousand will be severely impaired. We anticipate further that about 110 of the severe impairment cases (two per thousand) will turn out to be legally blind, and of this smaller number we estimate that approximately half will be known to local agencies.

c. Supplemental sample of the known blind. In addition to the household screening and interviews with visually impaired persons identified in our sample, we plan for purposes of comparison to interview a sub-sample of 200 legally blind persons drawn from the list of the Cleveland Society for the Blind. This list provides us with a relatively inexpensive way of increasing the number of our most severely impaired respondents. For analytical purposes, this group will, of course be kept separate.

d. The screening operation. Our basic assumption, borrowed from the National Health Survey and tested in our own pilot study, is that household interviews (either with the kin of visually impaired persons or with the impaired persons themselves) yield reliable measures of vision impairment as it is perceived by impaired persons or by other family members. Such measures are

not considered substitutes for clinical examinations, but they do provide us with a gross estimate of eye disorders which further investigation (clinical and non-clinical) will modify. In other words, we take as a starting point what people tell us about vision impairment, and we begin with a definition so broad that it is unlikely to miss many cases. As will be seen, we intend to subject these verbal reports to close scrutiny.

Specific procedures for screening vision impairment were developed and tested in our pilot study. Brief telephone and personal screening questionnaires will be identical and will include primarily an enumeration of all household members and an adaptation of the National Health Survey's check list of impairments. This information will be obtained from any adult member of the households in our sample who is qualified to give it. There will be no mention of "blindness" in this screening operation since we are particularly anxious to locate persons who for one reason or another may wish to conceal their condition or who may be unaware of it. Interviewers will be instructed to describe their call or visit as part of a general study of health in metropolitan Cleveland -- which in effect it is. They will then ask the respondent whether anyone in the household has any of certain conditions included in the Health Survey's check list of impairments -- which includes "serious trouble with seeing, even with glasses," "heart trouble or high blood pressure," "deafness or serious trouble hearing," etc. If the respondent reports any case of trouble seeing, we will then attempt for sub-sampling purposes to screen further for cases of moderate or slight impairments. A model for this step has been worked out by the National Health Survey in collaboration with the American Foundation for the Blind. Essentially, it involves making a preliminary determination of the severity of visual impairment in the course of the original household screenings. The justification for this is that the moderately impaired represent nearly 70

percent of all visual impairments and that, in view of our primary interest in severe impairment, it would seem wasteful to invest a corresponding proportion of our funds on this group. Thus, instead of personally interviewing all 770 of the moderately impaired whom we expect to locate in our four percent sample, we propose to sub-sample one-third (approximately 260) of them.

e. The problem of under-reporting. Various studies have shown wide discrepancies between the number of diseases or conditions reported in family interviews and those reported by clinical examination. In our pilot study in Cleveland, we made a special effort to look into the problem of under-reporting visual impairment by the household. What we did was sub-sample some 174 households which in our telephone screening had reported no cases of visual impairment. We then sent interviewers in person with the same screening questionnaire back to these homes to discover whether the telephone strategy had missed any cases. The result was that only one household out of the 174 recontacted showed a change, i.e. now reported a case of visual impairment where previously none had been indicated. It is worth noting, furthermore, that this single case was not severely impaired. In other words, our experience suggests that under-reporting is not likely to be increased because we rely on a telephone approach.

Still another problem has to do with under-reporting according to whether or not the respondent (in the screen interview) is himself impaired. Several epidemiological surveys -- among them the National Health Survey and the Baltimore study of chronic illness -- have shown that respondents are more likely to report their own conditions than those of other household members. While our pilot study tended to support this finding -- e.g. respondents reported more impairments for themselves than for non-respondents -- there was no evidence that this was due to use of the telephone strategy; when we controlled for age and sex, the difference between respondent impairment rates and non-respondent

rates tended to diminish. Nevertheless, it may be necessary for us to control for such under-reporting and weight the prevalence figures derived from non-respondent household members.

f. Personal interviews. All persons reporting severe vision impairment as well as a sub-sample of those with moderate or slight impairment and a sub-sample of the known legally blind (those registered by the Cleveland Society for the Blind) -- approximately 790 people -- will be contacted for intensive personal interviews about the extent of their impairment and other aspects of their health.* Whenever possible, personal interviews and examinations will be conducted with the visually impaired persons themselves. If personal interviews are out of the question for reasons of age or physical or mental condition, interviewers will be instructed to obtain as much information as possible from other responsible members of the household.

Interviewing and examination procedures have been pre-tested in our pilot study and with minor modifications will serve for the larger survey proposed here. Questioning of respondents will focus primarily on how they perceive their visual impairment, the past and present impact of the impairment on their mobility and activity, the history of any treatment received for the condition, and other aspects of health. The most important part of the interview consists of the distance and near vision tests. As in our pilot study, we propose to measure distance acuity with the Good-Lite Company's Translucent Eye Chart -- Model A. This is an inexpensive, portable, simple device with built-in fluorescent lighting which may be used with the 10-foot Sloan letters card (an advantage since relatively few homes have 20-foot living rooms). In our pilot study, an ophthalmologist instructed interviewers in the use of this test chart, and

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* The figure 790 represents the total of all cases which we expect to uncover in our screening (590) and the sub-sampling of 200 cases from the Society's list.

they experienced little difficulty in handling it. Preliminary analysis of data from our pilot study (in which we tested some 122 visually impaired persons) shows some, but by no means perfect, correspondence with the results of clinical examinations. However, differences may be due to variations in testing procedure. To measure near vision, we plan to use the Lebensohn near vision card (which was also tested in our pilot study). One desirable feature of this card is that it includes an example of 8-point or newspaper type and hence provides a validation of self-reported inability to read newspaper print (the National Health Survey definition of severe vision impairment).

g. Clinical validation. We of course do not regard the vision tests to be performed in respondents' homes by non-medical interviewers as substitutes for clinical examinations; rather they are intended to provide us with gross measures of vision impairment and a check on what people tell us about their eye conditions. To validate data obtained by our interviewers and provide more detail on etiology as well as the severity of vision impairment, we consider it essential to obtain more complete information from physicians who have examined our respondents within the recent past and also to arrange for complete ophthalmological examinations (conducted at our expense) which will take place after our own interviews. In our pilot study we asked all respondents who claimed that they had been examined within the past three years to sign a release authorizing us to request further information from their doctors; those who had not been tested in this period were then offered examinations conducted at our expense by a local ophthalmologist. In the larger survey we will follow a somewhat different procedure. Since (as our pilot study suggests) many patients tend to under-estimate the time which has elapsed since their most recent visit to a doctor and since old vision reports are unlikely to give a reliable picture of a condition which may change with time, we will ask for releases only

from respondents who claim that they have been examined within the past year. As a check on the reliability of these doctors' reports and our own vision tests, a random sample of one-third of all our respondents will be offered professional eye examinations at our expense. These procedures -- both the report form to be filled out by doctors whose patients have been examined within the past year and the arrangements for new clinical examinations -- will be developed in consultation with the Ophthalmological Advisory Committee of the Cleveland Society for the Blind.* This group played a similar consultative role in our pilot study.

h. The study of heart conditions. As noted above, one of the aims is to establish a model for screening and studying other chronic conditions. This model will be used in a pilot study of heart conditions reported in the screening operation (telephone and non-telephone). The purpose of the pilot study is to test the feasibility of establishing etiologic diagnosis of heart disease in a sample survey of this type.

In the 1962-63 vision impairment study, the screening questionnaires included an item on heart trouble and high blood pressure. The reported crude prevalence rate of these conditions was 63.7 per 1,000 in the total sample of households, quite close to the rate reported by the National Health Survey, 62.6 per thousand. In the telephone sample of households, the rate was only slightly higher than in the non-telephone sample -- 64.6 or 60.6 per thousand. Although the reliability check of telephone respondents reporting no vision impairment provided evidence of change in the answer to the heart disease and high blood pressure question, personal follow-up interviews in the pilot survey indicated that 40 percent responding yes by telephone changed to no, but that only 1 percent who said no to the telephone question said yes to the personal interview.

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* The report form will be patterned after NSPB's 1963 "Physician's Report of Eye Examination."

From this experience it appears that telephone screening is an efficient way to eliminate those without heart disease, if a negative response to the question about heart trouble or high blood pressure is a valid guide to the absence of the condition. More positively, it appears that telephone screening may be an efficient method for identifying diseased and nondiseased populations by name and demographic characteristics.

On this assumption the present pilot study proposes to look more closely at the problem of measuring and diagnosing cases of heart disease. The steps are to be taken as follows:

1. The basic sample will consist of the same group of households (telephone and non-telephone) for the study of vision impairment.

2. At the time of the initial interview, positive responses to the question, "Does anyone in the household have heart trouble or high blood pressure?" will be asked an additional set of questions. In a 4 percent sample of households in the Cleveland area, we expect 3,400 positive responses concerning heart disease.*

3. A subsample, approximately 10 percent, of all persons giving a negative response to the heart condition and high blood pressure question will also be asked the additional set of questions during the initial interview to determine more precisely whether they are or are not impaired by a heart condition.

4. The additional set of questions to be asked of all giving a positive response to the heart condition and high blood pressure question and to be asked of the 10 percent subsample of negative responses will assess their willingness to be examined and to cooperate. A subsample of approximately 100 cases will be offered clinical examination for the purpose of verification. The present plans do not call for any large scale clinical verification.

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* Based on the experience in the pilot study, the actual number should be no less than 2,200 and no more than 4,500.

The results of the initial screening should give an estimate of the magnitude of heart disease in a large metropolitan area. The pilot study will help correct the estimate. Problems of subsampling by age, race and sex should also be clarified by these methods. Logistic and technical problems in conducting pilot studies for verification of heart disease will be considered on the basis of the sampling and screening experiences. If it appears that it is possible to accurately identify individuals with heart disease in such a probability sample, the plans are to utilize the identified sample for additional epidemiologic and for special follow-up studies.

(2) Analysis of Data

a. Data processing. After editing and coding, all data from the screening of households (telephone and non-telephone), the personal interviews with visually impaired persons, and the medical reports and clinical examinations will be punched on IBM cards for processing and cross-tabulation.

b. Prevalence rates and characteristics of the impaired population. The first step in our analysis will be to determine the prevalence rate of eye disorders by severity of impairment for our total sample population; for the two major sub-samples -- telephone and non-telephone (which includes households with unlisted phones as well as homes altogether without phones); and for specific sub-groups, such as age, race, sex, and socio-economic.

c. Criteria for measuring degree or severity of impairment. Vision impairment is, of course a matter of degree. The question is how to determine the severity of the impairment. The criteria for sorting our respondents according to their degree of vision impairment will be derived from three primary sources -- our own vision tests, what respondents themselves tell us about their eye disorders, and clinical examinations and doctors' reports. In our pilot study we relied on a self-rating of vision impairment and on the acuity tests

which our interviewers administered in the respondent's household. On this basis we sorted our respondents into three groups: 1) the blind -- those who scored at 20/200 or worse in our own distance test; 2) the "severely impaired" -- or those who said they could not read newspaper print (the National Health Survey definition of severe impairment); and 3) the moderately impaired -- which included all those who did not fall into the first two categories. Our experience was that actual vision tests (even when performed by non-medical investigators) provide a necessary corrective for self-reported conditions. As a check against our own vision tests, in many but not all cases, we had reports from doctors or from clinical examinations which we arranged. As it turned out, the degree of correspondence between our own vision tests and the medical reports was not as high as we would have desired. Whether this resulted from the fact that our tests were administered by lay investigators or from other differences in the test situation remains to be determined. Our pilot study was a first attempt to attack this problem; in a larger survey we should be able to approach it more systematically -- e.g., by having different observors (medical and non-medical) perform vision tests on our respondents.

d. Activity and mobility limitations. While standardized vision test data are essential in determining the severity of eye disorders, they do not tell the whole story. One of the major assumptions underlying this survey is that vision impairment can be measured in functional as well as in clinical terms. Hence the necessity of determining the impact which the impairment has on daily activities and on physical mobility. Again, we shall borrow from the National Health Survey and its criteria for measuring the degree of limitation on activity and mobility. That survey has described varying degrees of limitation on activities (from total to partial inability to carry on major activities such as work and housework) and limitation on mobility (e.g., confinement to the

home, inability to get around alone, trouble getting around, etc.). What the Health Survey does is attempt to distinguish the impact which any single impairment or chronic condition (in this case vision impairment or eye disorder) has on activity and mobility. Thus, in any analysis of such limitations, it will be necessary to distinguish persons who are restricted primarily as a result of their vision impairment from those who are limited as a result of some other condition and from those handicapped by a multiplicity of conditions. While we looked into this problem in our pilot study, our sample was too small to permit any conclusions; it remains to be seen whether activity and mobility limitations correspond to the traditional classifications of vision impairment. If it turns out that the severely impaired as defined by the National Health Survey are no less restricted in mobility and activity than persons whom the law regards as blind, our survey will have confirmed one of the hypotheses that vision impairment can be defined functionally as well as clinically.

e. Identifying the "hidden blind". In Cleveland the hidden blind are those who are unknown to the Cleveland Society for the Blind, the leading voluntary agency providing services to the blind and the only organization with a list of blind persons. As in our pilot study, we shall match all verifiable cases of blindness which turn up in our sample against the list maintained by the Cleveland Society. In our earlier study, fewer than half of our blind respondents (persons who scored 20/200 or worse in our own vision tests) were known to the Society -- which has more than 2,000 on its list and which estimates the total blind population of metropolitan Cleveland at approximately 3,000. This unexpectedly high proportion of "unknowns" may very well have resulted from our small sample (which produced only 14 cases of blindness); we do not expect to find such a high ratio of unknown to known blind in the larger survey in which we expect to uncover over a hundred cases of blindness. In any

case, we attach great importance to the analysis of the characteristics and social and medical needs of this group, particularly in comparison with the known blind cases.

f. Differences between telephone and non-telephone samples. Special attention will be given to any differences in prevalence rates for vision impairment (and other chronic conditions) between the telephone and non-telephone samples. In our pilot study, as noted earlier, we found a much higher frequency of eye disorders in the non-telephone than in the telephone sample. However, in view of significant demographic differences between the two samples and the high sampling error for data from the non-telephone sample, we do not feel that a larger, more representative sample of non-telephone households would yield such high rates. Furthermore, non-telephone households include those with unlisted phones as well as homes altogether without telephones. Analytically, therefore, it will be important to distinguish not only between telephone and non-telephone populations but within the latter group as well -- particularly in relating demographic and other characteristics of our household sample to possible differences in prevalence rates within it.

g. Determining medical needs. We will have two major sources of data in estimating the medical needs of visually impaired persons in our sample. The first consists of what our respondents tell us. In our pilot study, 30 percent of our respondents said that they would like to have glasses or optical aids and 10 percent expressed a wish for medical treatment for their eye disorders. Such desires may be exaggerated, however, and will have to be critically evaluated. It is at this point that the information obtained from doctors and from the new clinical eye examinations of persons not recently tested will assume great importance. Such data will help not only in validating our own vision tests; medical reports will also give us a basis for an objective analysis

of our respondents' medical needs.

i. Follow-up studies. The over-all analytical objective is to identify the major physical and social characteristics of the visually impaired and also to identify the population groupings in which vision impairment is most likely to make itself felt and to affect everyday life. Achievement of this objective will then permit us to plan the more intensive follow-up interviews with sub-samples of our respondents in later phases of our research program. Hence the importance of determining not only the degree of vision impairment, but at least tentatively the nature of the impaired person's adjustment (personal, familial, institutional) to the condition.

C. Significance of the Research.

(1) Methodological. As we have observed earlier, we expect that our survey will provide a model for other studies of chronic conditions. This model has already been tested in our pilot study (in which we conducted a telephone screening of nearly 3,000 households); it will be employed again in a much larger telephone screening of vision impairment (in approximately 15,000 households); and it will be given a further test in a pilot study of heart conditions reported in the screening interviews. We did not and cannot rely exclusively on the telephone for screening purposes since a fairly large minority of households either have unlisted phones or lack them altogether and since we know that these households differ in socio-economic and other characteristics from telephone homes. But in view of the fact that at least three-quarters of all homes in the U.S. have phones (according to the Census Bureau), the use of this device for screening purposes has much to recommend it. As our pilot study and other surveys have shown, the telephone strategy is no less reliable than other strategies (personal and mail interviews) for certain fairly limited kinds of

health investigation. Perhaps most important, the telephone approach offers a rapid and economical means of collecting screening data from large populations. In our pilot study, the average cost of each telephone screening interview was $1.50, while personal screenings averaged $4.50. If, as we expect, the telephone strategy continues satisfactorily to meet the crucial tests of reliability and economy, it may well have wider application -- particularly in an age of mounting research costs.

(2) Substantive. The research proposed here and the studies which we plan to undertake in later phases of our research program represent the first systematic, comprehensive investigation of vision impairment in a large community. To begin with, they should help to close the gap in our knowledge about the prevalence of varying degrees of vision impairment. Above all, our research should provide a great wealth of data about the physical and social characteristics of the visually impaired population. This will include measures of prevalence rates by age, race, socio-economic group, general health characteristics, etc. While such information is of intrinsic interest, it will also have considerable practical value for Cleveland agencies concerned either with the prevention of blindness or with the rehabilitation of persons now experiencing serious eye disorders. For a long time, program planning by these agencies has been based on more or less educated guesswork about the numbers, characteristics and needs of the visually impaired. Our survey should help make such guesswork unnecessary, at least in one large metropolitan area. For the first time we will have data on the hidden blind -- those persons who are blind according to law but are unknown to local agencies; and on the severely impaired -- most of whom are not blind under the law. We do not assume that all of these persons desperately require medical or other services, but awareness of those who do will help agencies to plan programs accordingly. Our survey should help provide a more balan-

ced view of the impaired population, its size, characteristics and needs.

(3) Significance of heart conditions sub-study. It is important that new and useful research models for the study of impairments be developed and tested. The model to be used in the proposed study of visual impairment will be applied to the study of other impairments. If the application of this model to the study of heart disease and high blood pressure is feasible and successful, there will be two major results, namely: 1) descriptive data and prevalence rates for heart disease and for high blood pressure will be available, and 2) rosters of persons with heart disease of known etiology will be available for sub-sampling to test certain specific hypotheses about the condition.

D. Facilities Available.

All necessary facilities of the Departments of Sociology and Preventive Medicine of Western Reserve University will be made available for this research project. These include the services of faculty members as required, the availability of graduate students to work as research assistants, trained researchers at the Sociological Research Center, adequate space for housing, and I.B.M. and computer equipment for data processing. Installation of a data processing training program at the Sociological Research Building will make available basic equipment for most data processing operations. Also available are the computer units of the department of Biometrics and the Documentation Research Center at Western Reserve University and the computing center at Case Institute of Technology. These groups are available for consultation and use of their facilities for solution of statistical and data processing problems. The National Opinion Research Center of the University of Chicago will be available as in the pilot study for the collection of the data under the supervision of the professional staff. It is anticipated that the following groups who were of great assistance to the staff during the pilot project will continue to cooperate

with the major study. These groups include the Health Council of The Cleveland Welfar Federation, the Ophthalmological Advisory Committee and staff of the Cleveland Society for the Blind, the Cleveland Board of Health, and the Office of the Controller of Chronic Illness and Tuberculosis for Cuyahoga County.

2. Supporting Data.

A. Previous Work Done in This or Related Fields.

During the winter and spring of 1963, Western Reserve University, in collaboration with the American Foundation for the Blind, conducted a pilot study of vision impairment in Cleveland.* The National Opinion Research Center (University of Chicago) assumed primary responsibility for collection of data. The over-all purpose of our study was to test methods which we intend to use in the research proposed here. In this section we shall briefly outline the objectives, procedures, and findings of the pilot study. Further details will be found in the appendix attached to this application.

The specific aims of the study were first, to determine whether a telephone sample yields prevalence rates of vision impairment which are comparable to figures obtained by more traditional sampling methods (e.g., all households); second, to discover whether telephone interviewing provides reliable data about the extent of vision impairment, or whether there is under-reporting when results are compared with face-to-face interviewing; and third, to determine whether reliable vision tests can be administered in homes by non-medical interviewers.

A random sample of nearly 3,700 households was selected from the most recent Cleveland City Directory -- splitting into a telephone sample of approximately 2,800 homes and a non-phone sample (including unlisted numbers) of 900 households. All telephone listings were assigned to interviewers for screening,

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* Financial support for the study came from the National Institutes of Health and from the Cleveland Foundation.

but for budgetary reasons we were forced to sub-sample approximately one-third (309) of the non-telephone listings. Screening questionnaires, identical in both samples, contained a check-list of health items adapted from the National Health Survey (NHS), including "serious trouble seeing even when wearing glasses. Intensive personal interviews were conducted with persons reported in the screening (either by themselves or by other family members) as having serious trouble seeing. The primary objective of these interviews was to provide measures of the severity of vision impairment -- including subjective appraisals by respondents and actual tests of visual acuity (which were administered with the aid of the Good-Lite Company's electrically illuminated Visual Acuity Chart Translucent Model A, and the Lebensohn near vision card). Respondents who said they had been examined within the past three years were asked to sign releases authorizing us to approach their doctors for additional information, and a few persons who had not been examined during this period were invited to have clinical examinations at our expense.

Screening interviews were completed with nearly three-quarters of the originally assigned telephone listings, but with only 60 percent of the assigned non-telephone households. The reason for this was that we were forced to rely on an obsolete directory. Completed screenings yielded 152 cases of vision impairment -- of whom 127, or 84 percent, were successfully interviewed.

As compared with census data, our total household sample (telephone and non-telephone) was representative of Cleveland. On the other hand, the non-telephone sample differed sharply, particularly with respect to age, race and income.

Since we used the same criteria for screening purposes, the prevalence rates we found for vision impairment may be compared with NHS results. In our total sample (telephone and non-telephone) the prevalence of all cases of vision

impairment (23.8 per thousand) was fairly close to the NHS figure (19.8 per thousand). In our telephone sample the rate was even closer, 19.3 per thousand but in the non-telephone sample the prevalence was nearly twice as high -- 37.5 per thousand. This may result from the fact that non-telephone households scored low on socio-economic measures; we have reason to believe that the visually impaired in general are low in socio-economic status.

Apart from biological and social characteristics of the two populations (telephone and non-telephone) which may explain variation between them in the prevalence of vision impairment, there remains the question whether this variation can be attributed to the use of different interviewing techniques. To check the danger of under-reporting, we undertook a special reliability study and randomly selected for personal re-interviews a sample of telephone respondents who had not reported any cases of vision impairment. A total of 220 such checks were assigned to our interviewers, and 80 percent of them were completed. In these interviews the respondent was the same person who had served as the original telephone informant and the questionnaire included the same health items as in the original screening. We uncovered only one new case of vision impairment which had not been reported in the first screening, and further investigation revealed that this case was not severe. Our reliability check suggested, at least for vision impairment, that the difference between prevalence rates in our telephone and non-telephone samples was not caused by variation in the technique of interviewing.

The various measures of vision impairment which we obtained -- our own tests of near and distance acutiy, answers to a series of questions (in our follow-up interviews) about respondents' trouble seeing, reports from doctors -- gave us an opportunity to correlate verbal reports and actual tests of vision.

To begin with, slightly more than one-quarter (26 percent) of our visually impaired respondents said they were unable to read newspaper print even with glasses (the criterion by which NHS identifies its "severely" impaired population). NHS reports that an almost identical figure (28 percent) of all persons with vision impairments fall into this category. However, one-fifth of our respondents who said they were unable to read newspaper print were able to read 8-point (standard newsprint) or smaller type in the Jaeger near vision test. Conversely, almost one-fourth of those who said they were able to read newsprint could not read 8-point type on the Jaeger test. This is not conclusive evidence of unreliability in NHS criteria for defining severe impairment, especially since our near vision test was administered at 14 inches and since the NHS does not specify distance in its question regarding ability to read newsprint. Nevertheless, it suggests that any definition of severe impairment based entirely on what people say is subject to error.

To identify the blind, we relied on our own test of distance acuity: all respondents who tested at 20/200 or less were considered blind. We found that ten percent fell into this category -- a figure which would have been expected from the proportion of estimated blindness (two per thousand) in the total universe of vision impairment as defined by NHS (19.8 per thousand). Of this small blind group, less than half were listed by the Cleveland Society for the Blind; the remainder we have tentatively classified as "hidden."

Just as verbal reports of vision impairment were checked against the eye examinations which our interviewers administered in the home, so too we attempted to check our own vision tests against the results of clinical examinations. We obtained clinical data on two-thirds of our visually impaired respondents. For purposes of comparison, the results of our distance vision acuity tests (which had been administered at 10 feet) were converted into

standard 20-foot measurements. We found relatively little agreement between the results of our vision tests and what doctors reported.

Analyzing the cases of disagreement, we found that our interviewers consistently recorded more vision impairment than did the medical reports. How shall we explain such discrepancies? There is no evidence from our study that they result from the time lag between doctors' reports and our own tests. What remains to be explored -- in view of suspected differences in testing procedure -- is the general reliability of vision tests, not only between medical and non-medical investigators (as in our pilot study), but among medical observors themselves.

We conclude from our experiences in the pilot study that as the result of important demographic differences between the two populations, any impairment study relying on the telephone must supplement it with a sample of non-telephone homes -- as long as there is reason to believe that differences between the two groups may affect the prevalence of the condition. As for the reliability of telephone interviews for collecting impairment data, we conclude that this approach is just as dependable as any other (e.g., personal interviews) for screening purposes and for determining gross rates of vision impairment. Finally, we conclude that vision tests can be administered in the home by non-medical investigators, that they offer an important check against self-reported data on visual impairment, but that more research is needed on the general reliability of clinical vision testing. Given the limits which we set ourselves, we feel that our pilot study satisfactorily tested the procedures with which we propose to conduct a larger study of vision impairment in Cleveland.

(Section 2.B. Personal Publications omitted)

2.C. Pertinent Literature References

As noted earlier, there have been no community studies focusing primarily on vision impairment. However, there are available a number of estimates of the prevalence of vision impairment, as well as epidemiological surveys and other studies which deal with methodological questions raised by our proposed research. Among these works are:

(1) Hurlin, Ralph G., "Estimated Prevalence of Blindness in the United States and in Individual States, 1960," The Sight-Saving Review, Vol. XXXII, No. 1, Spring, 1962. In this study Hurlin estimated rates of legal blindness for the states by drawing on the actual count of blind residents in North Carolina and by weighing three factors -- the proportion of the total state population aged 65 and over, the proportion non-white, and the infant death rate. Estimated rates were then applied to the population of states. Some variation was found among them, with Utah having the lowest rate (1.39 blind persons per thousand) and Hawaii having the highest (3.98 per thousand). Hurlin's estimates have served as the primary source of information about the number of blind persons in the U.S. (which he estimates at 385,000).

(2) U.S. National Health Survey. Selected Impairments by etiology and activity limitation, United States, July 1959-June 1961. Washington, U.S. Department of Health, Education and Welfare, Public Health Service, 1962. Defining severe visual impairment as inability to read ordinary newspaper print with glasses, and basing its findings on interviews with a nation-wide probability sample of 76,000 households (250,000 persons), the National Health Survey estimated that there were approximately 988,000 severely impaired persons in the U.S. (5.6 per thousand). It also estimated that there were approximately 2,507,000 persons with other vision impairments (14.2 per thousand).

(3) U.S. National Health Survey. Heart Conditions and High Blood Pressure reported in interviews, United States, July 1957-June 1958. Washington, U.S. Department of Health, Education and Welfare, Public Health Service, 1960. In this earlier study, also based on a nationwide probability sample of households, the National Health Survey estimated that there were approximately ten million persons with a heart condition or high blood pressure (60.1 per thousand). Of this total, according to NHS, nearly half reported a heart condition (most of them without high blood pressure), and the remainder reported high blood pressure without a heart condition. Age, of course, turned out to be a crucial factor -- the prevalence of heart conditions increased from five per thousand for persons under 25 years of age to 186 per thousand for persons over 75.

(4) U.S. National Health Survey. Selected health characteristics by area: Geographic Divisions and Large Metropolitan Areas, United States, July 1957 - June 1959. Washington, U.S. Department of Health, Education and Welfare, Public Health Service, 1961. Here the National Health Survey compared the prevalence of selected chronic conditions by geographic division and among certain metropolitan areas. The prevalence of vision impairment varied somewhat among the regions (e.g., from 15.5 per thousand in East North Central States to 22.3 per thousand in South Atlantic States). Data available for only four metropolitan areas showed little variation in the rate of vision impairment.

(5) Ray E. Trussell, Jack Elinson and Morton L. Levin, "Comparisons of Various Methods of Estimating the Prevalence of Disease in a Community -- The Hunterdon County Study," American Journal of Public Health, February 1956; Jack Elinson and Ray E. Trussell, "Some Factors Relating to Degree of Correspondence for Diagnostic Information as Obtained by Household Interviews and Clinical Examinations," American Journal of Public Health, March 1957; Commission on Chronic Illness, Chronic Illness in a Large City: The Baltimore Study, Cambridge,

Mass., 1957; U.S. National Health Survey, Health Interview Responses Compared with Medical Records, Washington, U.S. Department of Health, Education and Welfare, Public Health Service, 1961; H. William Mooney, Methodology in Two California Health Surveys, Washington, U.S. Department of Health, Education and Welfare, Public Health Service, 1962. All of these studies show wide discrepancies between the number of diseases or conditions reported in household interviews and those reported by medical examination. As may be expected, the reliability of household interviews varies with the condition being reported. For example, as Trussell, Elinson and Levin indicate in their 1956 paper, diseases of the eye reported in household interviews are relatively well matched with clinical evaluation, while diseases of the respiratory system are poorly matched. On the other hand, in the same study relatively few of the eye disease cases found by clinical evaluation were matched with conditions reported in family interviews.

(6) Hochstim, Joseph R., "Comparison of Three Information-Gathering Strategies in a Population Study of Socio-Medical Variables," American Statistical Association, Proceedings of the Social Statistics Section, 1962, Washington, D.C. 1962; and "Alternatives to Personal Interviewing" (a paper presented before the Annual Meeting of the American Association for Public Opinion Research, Lake George, New York, May 17, 1963). These papers report a comparison of three interviewing techniques (telephone, mail, and personal) in a health survey conducted by the California State Department of Public Health. An area probability sample of Alameda County, California was divided into three sub-samples, and each was asked identical questions by means of the three interviewing techniques. The survey dealt with a fairly sensitive subject, cervical cytology, i.e., the Papanicolaou smear for early detection of cancer of the cervix. Comparing the three strategies, and particularly the telephone method with the personal interviewing method, the author reports identical substantive findings and equally high rates of return, questionnaire completeness and validity, as

confirmed by medical sources. On the other hand, the telephone interviews cost only half as much as the personal interviews.

(7) U.S. National Center for Health Statistics. Comparison of two vision-testing devices: A study to compare visual acuity as measured by the Sight-Screener and the Sloan Letter Chart. Washington, U.S. Department of Health, Education and Welfare, Public Health Service, 1963. This study reports a comparison of visual acuity as measured by the American Optical Company's Sight-Screener and the Sloan Letter Chart (an improved Snellen-type chart), controlling for fatigue and recall. The study group was non-random, consisting of 502 adults (age 17 through 79), with visual acuity of 20/200 or better. On the whole the scores obtained with the Sight-Screener matched those obtained with the Sloan tests; that is, no significant differences were found between them.